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The experiences of stroke survivors, and their families and unpaid carers, regarding goal setting within stroke rehabilitation: a systematic review of qualitative evidence.

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Abstract

Objective

The objective of the review was to synthesize the best available qualitative evidence regarding the experiences of stroke survivors, their families and unpaid carers, about goal setting within stroke rehabilitation.

Introduction

Clinical guidelines recommend person-centered goal setting in stroke rehabilitation but many barriers exist to its implementation. Individual differences and preferences, of both the stroke survivor and practitioner, may influence involvement in goal setting. A stroke survivor's relationship with close family members and unpaid carers can be powerful and could influence rehabilitation, recovery and goal setting.

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Inclusion criteria

The participants of interest were adults (over 18 years) who had experienced a stroke and undergone rehabilitation, and their families and unpaid carers. The phenomena of interest were the experiences of goal setting within stroke rehabilitation for stroke survivors', their families and unpaid carers. The context was stroke rehabilitation in acute and community hospitals, inpatient rehabilitation units and the community. Studies considered for this review were qualitative primary research studies and the qualitative portion of mixed methods research.

Methods

A three-step search strategy was used to identify English language qualitative primary research studies (both published and unpublished) through until November 2017. Two reviewers independently appraised the included studies using the Joanna Briggs Institute (JBI) Critical Appraisal Checklist for Qualitative Research. Studies were included if they achieved 50% 'yes' results for the methodological assessment. Data were extracted from the included papers using the standardized JBI qualitative data extraction tool. Data were synthesized using meta-aggregation.

Results

Four studies were included in this review, from which 44 findings were extracted. These were aggregated into 12 categories and four synthesized findings: (1) Person-centered goal setting is possible but often does not occur; (2) Practitioners shape the context of goal setting; (3) Practitioners need to listen to the person and know "who they are" – there is a need for an individualized approach to goal setting; (4) Recovery is ongoing and unpredictable. No findings reporting the experiences of

goal setting from the perspective of family or unpaid carers were found, therefore all findings represent stroke survivor experiences. The role of goal setting in self-management could not be extracted from the data.

Conclusions

Person-centered goal setting within stroke rehabilitation is both possible and rewarding but often does not occur. Goal setting contributes to the post-stroke rehabilitation experience and can be positively or negatively influenced by practitioners. Maintaining hope and a sense of forward momentum in recovery after stroke is perceived by stroke survivors as important and could be supported using goal setting that is tailored to the individual's needs and preferences. Future research should focus on refining individualized methods of goal setting in stroke rehabilitation and the role of the practitioner in this, including what skills are needed and how they can be acquired. The identified gaps in the literature about family members' and unpaid carers' experiences, and the role of goal setting in self-management, warrant further research.

Keywords

Goal setting; stroke rehabilitation; qualitative; experiences; stroke survivors.

Summary of Findings *(level 1 heading)*

1

Experiences of stroke survivors, their families and unpaid carers in goal setting within stroke rehabilitation **Bibliography:** Lloyd A, Bannigan K, Sugavanam T, Freeman J. Experiences of stroke survivors, their families and unpaid carers in goal setting within stroke rehabilitation: a systematic review of qualitative evidence. JBI Database System Rev Implement Rep 2018; ?(?);??-??				
Synthesized finding	**Type of research**	**Dependability**	**Credibility**	**ConQual score**
Person-centered goal setting is possible but often does not occur	Qualitative	Downgrade 2 levels†	Downgrade 1 level‡	**Very Low**
Practitioners shape the context of goal setting	Qualitative	Downgrade 2 levels †	Downgrade 1 level‡	**Very Low**
Practitioners need to listen to the person and know "who they are" – there is a need for an individualized approach to goal setting	Qualitative	Downgrade 2 levels †	Downgrade 1 level‡	**Very Low**
Recovery after stroke is ongoing and unpredictable	Qualitative	Downgrade 2 levels †	Downgrade 1 level‡	**Very Low**

† Downgraded two levels due to the dependability of primary studies (all studies had either no statement locating the researcher or this was unclear, two studies had unclear acknowledgement of their influence on the research findings, and for two studies the congruity between research methodology, methods and / or data analysis was uncertain).
‡ Downgraded one level due to a mix of unequivocal and credible findings.

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Introduction *(level 1 heading)*

Stroke is one of the leading causes of disability in adults and significantly affects the lives of individuals and their families, as well as the health and economy of a nation.[1,2] Stroke affects individuals in different ways and is associated with a wide range of disabilities.[3] It is recommended that individual needs and preferences are accounted for in the planning and delivery of stroke rehabilitation services, as part of a patient- or person-centered approach[4] (the term person-centered is used for consistency throughout this review, except for direct quotes and findings where the originating authors' terminology is adopted).

Person-centeredness is widely accepted as beneficial for people living with long-term conditions, such as stroke.[5] It has become an increasingly important concept in healthcare and rehabilitation,[6] with momentum building in the past decade.[5] Described as a "philosophy or approach to the delivery of rehabilitation services that reflects the needs of individuals … rather than professionals", it involves patients actively managing their own healthcare and rehabilitation, in collaboration with health professionals and service providers who "understand and respect their individual needs".[7(p1416)] Despite person-centeredness being widely recognized as a cornerstone in the management of long-term conditions, progress in implementation has been slow.[5]

Goal setting is recognized as a key element within rehabilitation.[8] It can provide a tool to support shared decision making[9] and self-management in healthcare,[10] and can assist people to find new ways of coping.[11] Involving stroke survivors in goal setting confers potential benefits within rehabilitation, such as improving patient satisfaction and the relevance of goal setting,[12] and is recommended within clinical guidelines.[13-15]

There exists a range of definitions of goal setting within rehabilitation. This review used the definition of a goal agreed upon by expert consensus: "A goal can be described as how things **will be** at some specified time in the future and that it is a desired state that requires both action and effort."[16(p338)] Goals may be long, medium or short term in nature, and these carry different characteristics. Long-term goals, also described as aims, are those "set at the limits of the foreseeable future".[16(p338)] They are built upon a stroke survivor's life values and priorities, and usually focus on social roles and participation.[16] Intermediate or medium-term goals, also described as objectives, should be linked to aims and usually focus on activities. Short-term goals, also described as targets, should be linked to an objective and may be set at any functional level.[16]

Agreement exists that involving stroke survivors in goal setting is beneficial. However, robust empirical evidence to support it remains lacking;[8] there remains debate as to how it should best occur,[16] and evidence suggests its use is not optimal.[17] Various barriers have been cited, including insufficient time and resources,[18] fear of losing professional authority,[19] cognitive and communication impairments, differences in staff and patient perspectives of goal setting,[20] and a lack of readiness to set goals.[21] Individual differences and preferences have been shown to affect a person's ability and

desire to be involved in goal setting, and hence different approaches to goal setting will likely be optimal.[20,22,23]

Stroke survivors and professionals have different perspectives on goal setting, use different languages to describe goals, and stroke survivors often feel unclear about their role in the process.[21] Rosewilliam et al., in their systematic review of stroke rehabilitation goal setting, reported that stroke survivors were motivated to be involved but perceived themselves as passive and not in control of their goals, which they attributed partly to a "prescriptive and inflexible" health system.[8(p505)] Plant et al. described goals set by patients as tending to be broad, involving hopes and aspirations, in contrast to goals set by staff members which tended to be short-term, impairment-focused and conservative, often "driven by financial and organizational pressures".[20(p924)] Katie Campion, a senior neurological therapist, gives an illuminating example of the importance of language in goal discussions. When discussing goals with a stroke survivor, he suggested his "goal"' was "to find the middle" (referring to the physiotherapist's quest to help him find midline in sitting). However, when asked what his "hopes for the future" were, he said, "To go back to work".[24(p1)] Thus, it is crucial to the advancement of person-centered goal setting that we understand the perspective of the stroke survivor more comprehensively and accurately.

There is also evidence to suggest that the impact of having a stroke on one's relationships with close family members is powerful, with close involvement of family being cited as a source of both encouragement and tension.[22] Whilst social connectedness can lead to better health outcomes and a sense of self,[25] having a stroke may also place increased pressure on family relationships[26] and stroke survivors may become more withdrawn to avoid burdening close family and friends.[27] Stroke survivors interviewed by Boger et al. identified informal (unpaid) carers as having the potential to help or hinder their ability to self-manage their condition, often acting as advocates for them.[28] Over recent years there has been an ongoing drive towards early specialist stroke rehabilitation in the home environment.[4,14,29] Given that many stroke survivors rely on help from family members for everyday activities,[30] it is important that the perspectives of the family and carers are better understood.

An initial search of the literature published prior to August 2014 was completed using the following databases: AMED, Embase, MEDLINE, BNI, CINAHL, Cochrane Library, PROSPERO, and the *JBI Database of Systematic Reviews and Implementation Reports*. Two systematic reviews that had considered stroke survivors' experiences of goal setting in stroke rehabilitation as part of a mixed review were identified. Rosewilliam et al.'s review of literature, up until June 2010, aimed to map the nature and extent of application of person-centered goal setting in stroke rehabilitation and to examine the evidence for any effects of its application.[8] Their investigation of stroke survivor experiences focused on barriers and facilitators, as well as comparisons with professional views. They did not include case studies. Sugavanam et al. reviewed literature until April 2011, looking at both the effects and experiences of stroke rehabilitation goal setting from the perspective of both stroke survivors and their treating professionals.[21] Both reviews provided helpful insights into the

perceptions of stroke survivors, in particular, comparing and contrasting them with those of professionals. However, since 2011 there have been significant developments within stroke rehabilitation and person-centered goal setting. For example, in the United Kingdom, national stroke guidelines[4,14] and audits of stroke care and rehabilitation[30] have been updated. Both these documents now have an increased emphasis on person-centered goal setting. They highlight the importance of involving stroke survivors in goal setting as much as is possible, and their family or carers where appropriate, helping them understand the process of goal setting, and providing them with support to define personal and meaningful goals.[4,14] In addition, it is increasingly recognized that a greater understanding of patient experience is required,[31] and a greater focus of research in this area is needed.[28] Therefore, a systematic review of up-to-date literature is warranted to capture any new published studies during this time of significant development within the field.

The objectives, inclusion and exclusion criteria and methods of analysis for this review were specified in advance and published in a protocol[32] and registered in PROSPERO (PROSPERO 2016:CRD42016036091). Deviations from the protocol are discussed in more detail in the methods and limitations sections (i.e. adopting a 50% cut-off score and the use of age limiters in the search). To the authors' knowledge, no other similar review has since been undertaken.

Objectives *(level 1 heading)*

The purpose of this qualitative systematic review was to synthesize the best available evidence on the experiences of stroke survivors, their families and unpaid carers, regarding goal setting in stroke rehabilitation.

The objectives were to:

1. Describe the experiences of stroke survivors, their families and unpaid carers in goal setting in stroke rehabilitation.

2. Identify whether stroke survivors, their families and unpaid carers consider the impact of goal setting on the person-centeredness of the rehabilitation approach.

3. Ascertain whether stroke survivors, their families and unpaid carers consider that goal setting enables them to effectively self manage their condition.

Inclusion criteria *(level 1 heading)*

Participants *(level 2 heading)*

This review considered studies that included adults (over 18 years) who have experienced a stroke and undergone rehabilitation in any rehabilitation setting, and their families and unpaid carers. The

latter included: family members either caring directly for the stroke survivor or living with them, and others providing direct care, but not being paid or related to the stroke survivor. Paid carers (non-family) or family members neither living with nor caring for a stroke survivor were excluded. Studies involving a mixed population were also considered where stroke specific data was presented separately and was thus extractable.

Phenomena of interest *(level 2 heading)*

This review considered studies that evaluated the experiences of stroke survivors, their families and unpaid carers regarding goal setting within stroke rehabilitation. Studies investigating goal setting as the entire focus or as a sub-section were considered. This review included the setting of goals within rehabilitation after stroke, of any timeframe, which fitted the description provided in the background section,

Context *(level 2 heading)*

This review considered studies that explored the experiences of stroke survivors who had undergone rehabilitation in acute and community hospitals, inpatient rehabilitation units and the community (either in their own homes or in a residential or nursing home setting).

Types of studies *(level 2 heading)*

This review considered any qualitative primary research study including, but not limited to, designs such as phenomenology, grounded theory, ethnography and action research. The qualitative portion of a mixed method study was also considered where the qualitative data was presented separately and was thus extractable.

Methods *(level 1 heading)*

Search strategy *(level 2 heading)*

A three-step search strategy was utilized to find published and unpublished studies.

Step 1: An initial limited search of MEDLINE and CINAHL was undertaken using initial keywords (Table 1). The text words contained in the title and abstract, and index terms used to describe articles were analyzed to identify more relevant keywords. Based on this, the search strategy was developed and refined through discussion with the team and an information specialist.

Step 2: The finalized search strategy was then applied to the following nine databases: MEDLINE, Embase, CINAHL, AMED, BNI, OTSeeker, PEDro; Social Care Online and HMIC (a Health Management and Policy Database from the Healthcare Management Information Consortium), the latter two include both published and unpublished studies. For some databases, such as PEDro, the search strategy had to be modified. Each electronic database was searched from the earliest date available until November 2017, to provide the most accurate synthesis possible (an initial search was completed through to January 2016, then the search was updated through to November 16, 2017). Search strategies are provided in Appendix I. As a translation service was not available, only studies published in English were considered for inclusion.. The search for unpublished studies also included: Open Grey, ProQuest Conference Papers and Proceedings and Google Scholar. However, this did not identify any new relevant studies. Screening of Google Scholar was stopped after the first 50 pages as no new relevant studies were identified.

Another focused search was conducted of MEDLINE and CINAHLfor papers by four authors who have written multiple papers in this field to ensure their complete works were considered: Fiona Jones, William Levack, Leslie Scobbie and Sheeba Rosewilliam.

Step 3: The reference lists of all reports and articles meeting the eligibility assessment were searched for additional studies.

(Place Table 1 here).

Study selection *(level 2 heading)*

Two reviewers initially scanned all titles and abstracts to exclude papers that did not align with the inclusion criteria. Full text articles were obtained for papers that met the inclusion criteria or where there was uncertainty, which were then independently assessed against the inclusion and exclusion criteria by two reviewers. Any disagreements were resolved through discussion and, where needed, a third reviewer was consulted. The articles selected through this process were then appraised for methodological quality using the JBI Critical Appraisal Checklist for Qualitative Research[33] and only studies achieving 50% 'yes' results for the methodological assessment were included in the review. The decision to adopt a 50% cut-off score in this review was made after the protocol was published, which is a deviation to the protocol; no guidelines exist to guide decisions about the exclusion of studies on the basis of methodological quality, with ongoing discussion and debate in this field.[34,35] Each review team must therefore agree based on a reasoned approach. The aim of a meta-aggregative review is to create recommendations for practice,[36] hence, on this basis, the review team chose the cut-off score with the aim of maximizing the ConQual level of recommendations produced (thus usefulness), whilst having sufficient papers for recommendations to be made. Drawbacks to this approach are discussed in the limitations section of this report. Any disagreements were resolved through discussion; a third reviewer was involved for one paper only.

Data extraction *(level 2 heading)*

Data were extracted using the standardized JBI qualitative data extraction tool.[33] The primary reviewer initially performed data extraction for each study independently, which was subsequently checked for accuracy by a second reviewer. The data extracted included specific details about the phenomena of interest, populations, study methods, outcomes of significance to the review question, and specific objectives. Findings were then extracted by the primary reviewer, checked for accuracy by a second reviewer, and discussed with a third reviewer to achieve agreement. A finding is defined by the JBI as "a verbatim extract of the author's analytic interpretation accompanied by either a participant voice, or fieldwork observations or other data".[36(p40)] Due to the variation in data reporting styles, findings were identified through repeated reading of the text, and extraction of findings included any distinct analytic observation reported by authors with an accompanying illustration. Each finding was assessed and rated as one of three levels of credibility:[36]

- Unequivocal - findings with illustrations beyond reasonable doubt and, thus, not open to challenge.
- Credible - findings with illustrations that are plausible and inferred from the data, but open to challenge.
- Unsupported - findings not supported by the data.

Data synthesis *(level 2 heading)*

The extracted findings and their accompanying illustrations were transferred into an Excel spreadsheet. This allowed findings to be viewed together, or in varying combinations, to aid the categorization process. The primary reviewer repeatedly read the findings before developing a set of categories, with findings allocated based on similarity of meaning. Categories were then reviewed, amended and agreed upon through a process of independent validation and group discussion, before being subjected to a meta-synthesis to produce a single comprehensive set of synthesized findings that could be used as a basis for evidence-based practice (achieved through group discussion). A ConQual score was generated for each synthesized finding to provide a rating for strength of evidence.[37]

Results *(level 1 heading)*

Study inclusion *(level 2 heading)*

The comprehensive search of the literature yielded 8603 results; 8404 were identified from the search strategy and 199 through author searching (Appendix I). In addition, thirty-five papers were identified through hand searching the reference lists of included papers. After removal of duplicates, 7929 titles and abstracts were screened for relevance and 7841 were excluded. It was not possible to exclude

duplicates from the search results for OpenGrey and ProQuest Conference Papers and Proceedings databases, as software to complete this task was not available. The full texts of the selected 88 papers were assessed against the inclusion criteria using a screening tool developed for this review (Appendix II), resulting in the exclusion of a further 81 articles (Figure 1).

Reasons for exclusion typically fell into one of the following categories:

i. A qualitative study where goals were mentioned or discussed but goal setting was not the focus, for example, where a self-management program was evaluated but the content of that program was not explicit so it was not clear whether goal setting interventions were used (exclusion criteria 3).

ii. A qualitative study where goals were discussed but the experience of stroke survivors or their family/unpaid carers was not explored, for example, where the focus of the study was to describe the content of goals not the experience of setting goals (exclusion criteria 1).

The seven remaining papers were critically appraised and three were excluded for insufficient methodological rigor. Thus, four papers were included in this review. (Figure 1)

(Place Figure 1 here.)

Methodological quality *(level 2 heading)*

Two reviewers used the JBI Critical Appraisal Checklist for Qualitative Research[33] to independently assess the seven articles for methodological quality. An article was included if it achieved 50% 'yes' results for the methodological assessment, as agreed by both reviewers (Table 2).

Three papers were excluded on the basis of methodological quality (Appendix III). All three achieved 0 or 1 out of 5 marks for dependability questions (Q2-4, 5, 6). In one study[39] the method of analysis, i.e. content analysis, was considered to lack congruence with a philosophical perspective that suggests people construct knowledge out of their experience, i.e. learning by doing (constructionism). The essence of the experience (learning) may be lost by a focus on the words at a content analysis level. There was no statement locating the researcher culturally or theoretically and there was no audit trail to support the participant quotes provided. In another study[40] insufficient detail was provided regarding philosophical perspective, methodology and method of data analysis in order to determine congruence, and participants' voices were not considered to be well represented. The author described collecting quality of life data in the methodology, but this data was not clearly reported, providing a partial picture of findings. In the third study[41] insufficient detail was provided regarding philosophical perspective and methodology for determining congruence. There was no statement locating the researcher theoretically or culturally.

Of the included studies, all achieved 2 or 3 marks out of 5 for dependability questions (Q2-4, 5, 6); no study included a clear statement locating the researcher culturally or theoretically and only one[42] clearly addressed the influence of the researcher on the research. Two studies had clearly stated the

philosophical perspective and specific qualitative methodology from which to determine congruence.[17,25] Two studies did not state their philosophical perspective[22,42] and congruence between methodology and research aim,[22] or the methodology, methods and data analysis[42] were not clear. In all included studies, participants' voices were well represented and conclusions grounded in this data. The ethical approval process was clearly described in one study,[42] stated as not applicable in another,[25] and partially reported (i.e. unclear) in the remaining two papers.[17,22]

Thus, four papers were included in this review.

(Place Table 2 here).

Characteristics of included studies *(level 2 heading)*

The four included studies (Table 2) are described briefly here (Appendix IV provides additional details).

- **Brown et al[22]** conducted a qualitative descriptive study to explore patient experiences of goal setting. They interviewed patients, in their own homes, 12 weeks after discharge from inpatient stroke rehabilitation in New Zealand (n=10).
- **Levack et al**[17] employed a constructivist grounded theory approach to study the application of goal setting in an inpatient stroke rehabilitation setting in New Zealand. They used multiple data collection methods and involved patients (n=9), their families (n=7) and treating clinicians (n=28) as participants (total n=44) (only the stroke survivor data was included in this systematic review).
- **Martin et al**[25] used qualitative semi-structured interviews with people with severe Acquired Brain Injury (ABI), including three stroke survivors (only the stroke survivor data was included in this systematic review), residing in a New Zealand residential care setting (n=5), to explore life goal planning in rehabilitation from an interpretative phenomenological perspective.
- **Rosewilliam et al**[42] used multiple qualitative methods of data collection to explore whether the current goal setting practice in acute stroke rehabilitation was patient-centered, and what factors influenced this. Seven sets of data were collected from stroke survivors and from one of their treating professionals from an acute stroke unit in a large teaching hospital in England (only the stroke survivor data was included in this systematic review).

Review findings *(level 1 heading)*

Results of the meta-synthesis of qualitative research findings *(level 2 heading)*

From the four included studies, 57 findings were extracted with accompanying illustrations (Appendix V). Findings that reflected the perspective of practitioners, rather than stroke survivors, their family or unpaid carer, or were about rehabilitation in general rather than experiences of goal setting (n=13)

were excluded. In one study[17] the reported data was pre-dominantly observational or from the practitioner perspective and only one finding with a supportive illustration could be extracted. Thus, 44 study findings were included in this review, all with a credibility assessment of either Unequivocal (n=32) or Credible (n=12). These were aggregated into 12 categories, based on similarity of meaning, and then synthesized into four findings: (1) Person-centered goal setting is possible but often does not occur; (2) Practitioners shape the context of goal setting; (3) Practitioners need to listen to the person and know "who they are" – there is a need for an individualized approach to goal setting; (4) Recovery after stroke is ongoing and unpredictable. Medical and health professionals and other staff members are collectively termed practitioners, as a 'catch-all' term, for the purposes of this review.

In this meta-synthesis, there were no study findings that represented the voice of family members or unpaid carers regarding their experiences of goal setting. Therefore, all findings presented represent the voice of the stroke survivor. Where possible the actual participant's words were used throughout the analysis to help reviewers stay grounded in the data, and so their perspective. Double quotation marks indicate where the stroke survivors voice has been directly represented, and single quotation marks represent quotes from study authors. The synthesized findings are presented in an order designed to aid readability and understanding rather than a hierarchical order.

Synthesised finding 1 – Person-centered goal setting is possible but often does not occur (Table 3) *(level 2 heading)*

Categories *(level 3 heading)*

1. Person-centered goal setting is possible and "rewarding", but does not always *happen* *(bold)*

Discussions about goals and recovery prospects had the potential to be collaborative and person-centered, like an "equal interaction", and that this was "rewarding" (Colin)(1r)[22(p1023)] when it happened. However, although the practitioners were, at times, perceived to be making an effort to be person-centered, that aspiration did not necessarily translate into practice:

"They [the physiotherapists] certainly had an interest in the game of bowls and the fact that I was you know a bowler… … they studied me… But the exercises I was performing didn't change, they were the same exercises prior to seeing me bowl and they kept up the same exercises after. They didn't change them at all." (Interview with P3, three months after discharge)(2h)[17(p211)]

2. There is a spectrum of person-centeredness, which depends on a variety of factors – intrinsic and extrinsic to the stroke survivor *(bold)*

Intrinsic factors to the stroke survivor which could affect the person-centeredness of the goal setting approach included the attitude and personality of the stroke survivor, and their desire to be involved in goal setting. Some reported wanting to get on with their own goals:

"…well because my goals were my goals…the less I talked in hospital the better I was, really. I don't want to keep going over and over and over. Within myself I have worked out a wee sort of plan which may or may not work and I don't want to be continually patted on the back or commiserated with – I just want to be able to set it in motion." (Janet)(1s)[22(p1023)]

Conversely, others saw the practitioner as the expert and were happy to follow their lead; *"I was the novice",* commented Ian*, "and they were the professionals". (1q)* [22(p1023)]

Extrinsic factors affecting person-centeredness of goal setting included: the approach of the treating practitioner, whether they listened or not; the busyness of the ward; and the involvement of family and friends. These could either be a source of encouragement or tension, with one participant describing a feeling of *"…constantly battling people's perceptions of what you're capable of and what you should be doing". (Ian)(1m)*[22(p1023)]

3. Tension between ambitious and conservative goals, which could lead to goals kept in secret*(bold)*

Some stroke survivors described wanting to set very ambitious goals, even if they knew they might not achieve them, as this could foster hope and motivation and give comfort, feeling that this could potentially boost performance. This was in contrast to their perception that practitioners wanted to set conservative goals and might warn against very ambitious goals. Consequently, stroke survivors would sometimes set themselves an ambitious goal but keep it a secret:

"The physio said to me – look, we'll do the best we can but I don't want you to over-expectate (sic) because if you don't do it, I don't want you to come crashing down, you've got to realize that you might plateau off. So, at the back of my mind I always thought yep I can see that, but I'm going to bloody well walk before Christmas. I just didn't share it with anyone. I just told myself." (Janet)(1w)[22(p1022)]

(Place Table 3 here.)

Synthesized finding 2: Practitioners shape the context of goal setting (Table 4) *(level 2 heading)*

Categories *(level 3 heading)*

1. Practitioners can either "encourage" people or "deflate" them *(bold)*

Practitioners were perceived to have potential to contribute positively, or limit, a stroke survivor's pursuit of their own goals. Through their interactions they could raise or diminish a stroke survivor's sense of hope:

"I heard the words and they had some impact, but there was still an underlying spirit, if you like, thinking well let's see what we can do. Not let's – let's not say what we can't do … it is not wise to set negative goals, or set limitations when you know [stroke recovery] is unpredictable … learn how to encourage people and not deflate them." (Colin)(1x)[22(p1024)]

Some stroke survivors reported positive experiences of feeling listened to, and that a positive relationship with practitioners was desirable as it would foster further support and help: *"… they could see that I was trying [so] they helped me more and more" (Bob)(1o)*[22(p1023)]

2. Empowered/disempowered *(bold)*

Stroke survivors' felt either empowered or, more commonly, disempowered with respect to setting goals and making decisions during their stroke rehabilitation. Barriers existed for stroke survivors to enact autonomy, including a lack of opportunity to have discussions or gain information, or feeling that they had little or no control over when these opportunities arose and so were not prepared: *"…because you are in your bed all you do is function, you're eating… and wait for the doctors to come around … you don't know when ... You will forget the question by the time they come…" (Patient 1.9)(4j)*[42(p514)]

Some participants perceived staff as too busy and felt the overriding goal was to get them discharged, due to pressure on beds: *"I think their goals are to get you off. I don't think the hospital has got enough (staff). After me there's another queue coming in..." (Patient 2)(4g)*[42(P515)]

Others felt there was a *"set plan"* they had to work to *(Gary)(1p),*[22(p1023)] and didn't feel able to make independent choices about how to spend their time, *"…without having to beg and plead." (Megan)(3k).*[25(p1238)] One stroke survivor described not wanting to burden staff with her goals and aspirations feeling she *"…should be grateful for, and encourage the help…" (Megan)(3i)*[25(p1238)] Another was looking forward to life after hospital to be able to set their own agenda: *"You see my time here is your time. I have to abide by your rules. When I am out of here I abide by my rules..." (Patient 2)(4c).*[42(p513)]

(Place Table 4 here.)

Synthesized finding 3: Practitioners need to listen to the person and know "who they are" – there is a need for an individualized approach to goal setting (Table 5) *((level 2 heading))*

Categories *(level 2 heading)*

1. Goal setting is not 'one-size-fits-all' *(bold)*

Stroke survivors used varying terminology and descriptions to talk about goals and, for some, the concept of goals was broad. Different individuals described how different types of 'goals' were of benefit to them, achieving different purposes, at different times and in different situations. For example, for some, small, short-term or daily goals were perceived more useful rather than goals set *"…in the future too far ahead" (Fleur)(1c).*[22(p1022)]. Others however described the importance for them to set longer-term, ambitious goals to improve motivation and maximize gains:

"I said to [the physiotherapist] well I want you to set the bar right to the top. Because if I can't get, I said because I may not be able to get there but if you set it at the top I might get it three quarters of the way, or 90%. I said, but if you set 75, I may only get to um 60%." (Andrew)(1e)[22(p1022)]

Others described experiences that had represented a *"triumph"* or *"revelation" (Colin)(1y),*[22(p1024)] which was a special and important achievement that they remembered as an important marker in their recovery, and which served to '*boost confidence, motivation and hope for further recovery'.*[22(p1024)]

"… A little triumph I had yesterday, um I cut my fingernails twice with this hand. That's the way of gauging progress you know, in something like that … I can say oh in those two weeks that has significantly changed. So that's you know, a boost." (Colin)(1y)[22(p1024)]

The notion that goal setting after stroke could not be 'one-size-fits-all' was both implied, through the many and varied descriptions of how goal setting was perceived, and also stated explicitly by one participant:

"Work back from personality, if you like, to the goals … you know, listening to the words, listening to the patient, um knowing who they are is important … you'd feel involvement rather than um, how can I put it, [that goal setting was] a bureaucratic exercise." (Colin)(3t)[22(p1024)]

2. What makes me "me" – the importance of knowing the individual person in order to set goals of 'special importance' *(bold)*

Some stroke survivors expressed a need to work towards goals that were individual and meaningful to them in terms of what they enjoy doing, not just what they need to be doing: *"… I'm not fighting for my life, but I'm just fighting for my lifestyle, in other words what makes me "me" ". (Colin)(1u)*[22(p1024)]

Where these goals were unlikely to be achieved there was still comfort and satisfaction to be gained from dreaming about them:

"I think as normally as possible and then I'll go to bed at night and think oh well I won't be doing that really. But that's okay because at sometime I will. And if I don't do them, I can dream about them … I can lie in bed and dream about climbing a mountain, cos I just adore mountains …" (Janet)(1v)[22(p1024)]

3. Importance of "being part of things" *(bold)*

For some stroke survivors there was value in being connected to others and the world through relationships and meaningful participation, to support their enduring and evolving sense of self, and as both a method to achieving goals and a goal in itself:

"It's very important for me to be able to help people ... it's obviously good for them that I'm helping them, but maybe this is selfish, it's very, very important for me that I'm helping them." (Megan)(3c)[25(p1237)]

(Place Table 5 here.)

Synthesized finding 4: Recovery after stroke is ongoing and unpredictable (Table 6) *(level 2 heading)*

Categories *(level 3 heading)*

1. Being simultaneously changed, unchanged and changing[25] *(bold)*

Some stroke survivors felt they were in some ways 'unchanged' and the same person with the same personality as prior to their stroke,[25(p1237)] but in other ways they were *"terribly different",* particularly with respect to their ability to achieve everyday functional tasks and their dependence upon others for support. *(Megan)(3g)*[25(p1237)] For some, it was their ability to achieve their goals that had changed:

"No, I'd say the [things that are important to me] are pretty much the same, but it's my ability to be able to achieve them which has changed." (Megan)(3d)[25(p1237)]

However, there was also a sense of recovery as an ongoing process, with stroke survivors experiencing ongoing and gradual change over time:

'For example, Bridget referred to her past inability to "walk, talk, or do anything" and contrasted this with the statement: "now I'm working for them".' (3h)[25(p1237)]

2. Unpredictability *(bold)*

The uncertain and unpredictable nature of recovery after stroke was perceived to lead to difficulty knowing what goals to set. Individuals responded differently to this uncertainty; some preferred to set very ambitious goals to achieve their maximum performance, others opted for small short-term goals, and for others it led to a reluctance to commit to goals: *"Goal setting has always been a bit of a problem I feel, because I don't know what sort of rate, you know, I'm going to be rehabbing at." (Andrew)(1b)*[22(p1022)]

3. Day-by-day (forward) momentum *(bold)*

Keeping the momentum forwards on a day-to-day basis, either through daily goals and objectives or longer-term hopes and dreams, was considered important.

"I just took it day by day and I sort of set myself certain things to do… if I felt I got through those fairly good, easily, I just took another step forward sort of style." (Bob)(1a)[22(1023)]

4. Recovery is a natural process *(bold)*

Recovery after stroke was considered a natural process, with the suggestion that the goals to be worked on were 'common sense'[22(p1022)]: *"…it was kind of apparent what needed to be worked on". (Ian)(1h)*[22(p1022-3)]

(Place Table 6 here.)

Discussion *(level **1** heading)*

The aim of this systematic review was to synthesize the best available qualitative research evidence on the personal experiences of stroke survivors, their families and unpaid carers, regarding goal setting in stroke rehabilitation. Four synthesized findings were aggregated from 44 study findings identified from four qualitative studies. Due to the dependability of primary studies and the credibility of the findings (i.e. being of mixed credible and unequivocal ratings), the synthesized findings received ConQual scores of very low levels of evidence. This discussion examines the synthesized findings, in relation to the aim and objectives of this review, to consider possible implications for practice and further research. It focuses solely on the experiences of stroke survivors because no findings representing family or unpaid carers were identified in this review, and it was not possible to extract data specific to goal setting from the studies about self-management interventions.

Person-centered goal setting is possible but often does not occur *(level 2 heading)*

The experience of the stroke survivors was that the barriers to person-centered goal setting often outweighed the facilitators. This resonates with three systematic reviews of goal setting in stroke rehabilitation.[8,20,21] Sugavanam et al.[21] found more barriers to goal setting than facilitators, Plant et al.[20] suggested that current goal-setting methods in early stroke rehabilitation were not fit for purpose, and Rosewilliam et al.[8] concluded that person-centered goal setting was minimally adopted within stroke rehabilitation due to various barriers.

Nonetheless, a small number of findings indicated that stroke survivors experienced person-centered goal setting within stroke rehabilitation, and that positive communication with practitioners could create a more equal interaction, fostering hope and greater satisfaction. Other studies have reported the potential positive psychological effects of goal setting.[43] A mixed methods study of a mixed population in a neurological rehabilitation unit found that it was possible to increase patient participation in goal setting, and that this resulted in fewer, more relevant goals being set (reflecting the patient's own choices), and increased patient satisfaction with the process.[12] In their systematic review, Plant et al. [20] reported that good communication (early, frequent, active) between patients and family and practitioners that were positive and encouraging acted as a facilitator to goal setting within stroke rehabilitation. A systematic review of shared decision making within rehabilitation goal setting reported patients enjoyed goal setting with clinicians, and found it supported feelings of better coping and personal control.[44] The provision of materials to support patients to identify goals has been reported as a facilitator to goal setting.[20] Scobbie et al.[45] described and evaluated a theory-based model for person-centered goal setting in community stroke rehabilitation (G-AP framework). They found stroke survivors described the identification of personal goals as motivating, with goal achievement leading to increased confidence. They also reported a more positive relationship with practitioners which they felt was a significant facilitating factor in their recovery.

Practitioners need to listen to the person and know "who they are" – there is a need for an individualized approach to goal setting *(level 2 heading)*

The stroke survivors in this review could identify when the goal setting and rehabilitation approach was either tailored to address their individual needs or set on a pre-determined schedule; they preferred a more individually tailored approach. This suggests that stroke survivors considered the impact of goal setting on person-centeredness of their rehabilitation. This resonates with Plant et al.,[20] who reported that individually tailored goal setting processes facilitate goal setting in stroke and ABI rehabilitation. They suggested that the locus of goals needs to be individualized and could be either more 'patient-led' or 'therapist-led', potentially influenced by stage of recovery, professional approach, service demands and resources. This links with findings in this review suggesting that a spectrum of person-centeredness in goal setting approach exists, with respect to stroke survivors' desire to be involved and the approach of treating practitioners within the wider bio-psychosocial context. This also resonates with other published evidence describing a continuum of goal setting approaches, from 'patient-led' at one end to 'health professional' led at the other, along which person-centered goal setting was possible.[23,45,46] Cameron et al.,[46] in their ethnographic study, highlighted active and reflective listening by practitioners as being crucial to achieving the level of collaboration required for successful patient-centred goal setting, recognizing that most patients have the ability to direct goal setting conversations when supported.

This review has highlighted that different goal types and goal setting approaches are preferred by different individuals, to achieve different purposes, at different times or stages of recovery. Levack et al.[19] conducted a systematic review in which they identified four main purposes for goal planning in rehabilitation, and highlighted the importance of distinguishing between purposes in goal planning research. Although the goal purposes described by the stroke survivors in this review do not align with those in Levack et al.,[19] there are similarities in that different purposes for goal setting were articulated, for example, using short-term goals to create a day-by-day momentum and bolster mood, or setting highly ambitious goals to maximize performance. Sugavanam et al.[21] found that patients and professionals tended to set different types of goals, with patients goals tending to be broader and more optimistic with respect to outcomes. This echoes the experiences of stroke survivors in this review who, for example, described some day-to-day goals set by clinicians as 'common sense' and 'survival needs',[22(p1022)] and others who referred to their 'triumphs' as goals.[22(p1024)] These 'triumphs' were goal achievements identified retrospectively and do not fit the definition of a goal stated earlier in this review,[16] but better fit the definition of mastery experiences. These were described as 'experiences of personal success in a particular task or skill … made more influential when attributed to the individual's own efforts and persistence', which could positively influence self-efficacy, a concept which has been very influential to self-management programs. [47(p269)] This suggests it is important for practitioners and stroke survivors to find and agree on a common language in goal setting in order to work together effectively, and potentially for practitioners to be open to re-framing how they talk about goals.

Practitioners shape the context of goal setting *(level 2 heading)*

The stroke survivors' perspective in this review suggested practitioners had the potential to shape the context of goal setting in both positive and negative ways; they wanted practitioners to listen to them and find out more about who they really were. A positive and engaging therapeutic relationship seemed to foster more of the same, whereas a relationship where practitioner and stroke survivor goals were not aligned led to discontentment, resignation and sometimes to the stroke survivors keeping their own goals secret. Cameron et al.[46] found practitioners had greater influence on the goals developed than patients, highlighting practitioner self-awareness as a key factor in the success of goal setting. However, they also reported a perceptual-practice gap where practitioners may overestimate the extent to which their goal setting was person-centred.

Bright et al.[48] highlight how engagement is co-constructed and dynamic; each party is influenced by the other's actions and their own interpretation of the other's engagement. They suggest more attention should be paid to practitioner dis-engagement, alongside the more commonly discussed patient dis-engagement, because these are inter-related concepts; engagement and dis-engagement often mirror each other. They describe practitioner dis-engagement as complex and accompanied by stigma, with patients perceiving dis-engaged practitioners as likely to be more detached and focused on service requirements. In contrast, engaged practitioners were perceived by patients to be passionate about their role and more likely to personalize their work to the needs and preferences of the individual. In the current review, the stroke survivor's desire, or perhaps need, to be listened to and feel their goal setting approach was personalized may be linked to the need for an engaged practitioner. If engagement is mirrored, and engagement style varies between individuals, this may add to the complexity of achieving fully engaged, and person-centered goal setting.

Recovery after stroke is ongoing and unpredictable *(level 2 heading)*

The sense in this review that stroke recovery is an ongoing and unpredictable process, and that an individual can be simultaneously 'unchanged, changed and changing',[25(p1237)] leading to challenges in goal setting, is not isolated. Satink et al.[49] describe how both continuity and discontinuity in roles co-exist after stroke. They explain how stroke survivors express their hope to return to pre-stroke life, including connectedness with self and others, as a goal in the future; for some, this is a way of managing life on a day-to-day basis. This resonates with stroke survivors in this review. Some responded to the uncertainty of recovery after stroke by setting very ambitious goals, regardless of whether they could achieve them, whilst others focused on daily goals to sustain the momentum. The Life Threads Model describes how our sense of self is supported by stories we tell ourselves; some life threads represent stories that persist throughout our lives, and others come and go, with

connections to significant others also being represented.[50] When a person has a stroke, some of these life threads are severed, and the stroke survivor must, over time, create links between a known past and an unknown future to create a new current and future sense of self.

Excluded studies *(level 2 heading)*

Three studies were excluded from this review. Of note, their findings resonated in many ways with the findings of this review. Laver et al.[40] found stroke survivors to vary in their readiness to participate in goal setting, depending on individual preference and stage of their rehabilitation. Howe et al. reported that family members of people with post-stroke aphasia also placed value on being provided with 'a sense of hope' and that practitioners had an important role in this.[39(p515)] Berg et al.[41] reported an overall lack of focus on collaborative goal setting and that individual variation existed between stroke survivors in terms of goal type and the desire to be involved in goal setting. These findings resonate with the first three synthesized findings of this review in particular: 1)Patient-centered goal setting often does not occur, 2) Practitioners shape the context of goal setting, and 3) There is a need for an individualized approach to goal setting. Areas of difference included a greater focus from participants on the vagueness of rehabilitation,[41] and the need for greater inclusion of family members in goal setting (with reference to stroke survivors with aphasia).[39,46]

Strengths and limitations *(level 2 heading)*

The strength of this review is its description of the personal experiences of stroke survivors with respect to goal setting in rehabilitation. The focus on primary qualitative research and solely on stroke rehabilitation goal setting allows the conclusions and recommendations for practice to be more transferable. This review has also highlighted the paucity of data about the experiences of family members and unpaid carers, and the impact of goal setting on the stroke survivors' ability to self manage, which provides directions for future research.

In terms of limitations, only a small number of studies were eligible for inclusion. It could be argued that a more lenient cut-off for methodological quality for the studies should have been adopted. The role of critical appraisal of qualitative studies in systematic reviews is an on-going cause for debate.[34,35] The decision to exclude studies that were determined to be of insufficient methodological quality may therefore be considered by some to be contentious, particularly given that the included studies have not rated highly in terms of methodological quality, and that there is a paucity of studies on this topic. However, with a meta-aggregation the aim is to produce recommendations for practice, therefore it is deemed important to appraise quality to ensure output is as useful as possible.[35] Whilst some may contend that the excluded studies may have offered useful contributions to this review, it has been demonstrated that the exclusion of studies of lower methodological quality had no meaningful effect on the synthesis.[51] When choosing a 'cut-off' point for methodological assessment

no clear guidelines existed. It was up to the review team to come to an agreement based on the available literature and the aims of the study; our decision was to only include those scoring 50% or more on the quality assessment tool. Future research might benefit from post synthesis sensitivity analysis "to assess whether anything, no matter how apparently insignificant, might have been lost to the synthesis by excluding inadequately reported studies".[51 (p.1431)] This was not within the scope of this review.

The ConQual scores are very low for the synthesized findings in this review, thus any translation into practice must be tentative. Yet, they do resonate strongly with the wider body of published literature, as reported in the discussion. Transferability is also limited by geographical and sampling considerations. Three of the four studies were conducted in New Zealand,[17,22,25] and three of the four studies involved a mixed population.[17,25,42] For example, in one study only one finding was relevant to the research question.[17] Equally, only studies published in the English language were included, so relevant studies in other languages may have been missed, and the searches in OVID MEDLINE and Embase databases used a limiter of 19 years plus for the adult age group, which may have led to articles indexed for 18 plus, or incorrectly indexed, being missed.

Conclusion *(level **1** heading)*

This qualitative systematic review has synthesized evidence about the personal experiences of stroke survivors with respect to goal setting in rehabilitation and has found that stroke survivors do consider the impact of goal setting on person-centeredness of their rehabilitation. They experience person-centered goal setting as both possible and rewarding, but as often not occurring, with barriers outweighing facilitators. The practitioners working with stroke survivors are perceived as having a powerful role, which can positively or negatively shape the goal setting, and thus the rehabilitation experience. Stroke survivors express a need for goal setting to be tailored to individual needs and preferences and, for that to happen, practitioners need to take the time to listen well. Recovery after stroke is perceived as an ongoing, natural but unpredictable process, to which stroke survivors respond in different ways. However, there appears to be a shared experience of the importance of maintaining hope and a forward momentum in recovery, and that goal setting could serve as a useful tool to support this if used well. This review highlights a paucity of data relating to the experiences of family members and unpaid carers, and to the impact of goal setting on stroke survivors' ability to self manage, thus providing directions for future research.

Recommendations for practice *(level 2 heading)*

- Individual practitioners and providers of inpatient stroke rehabilitation services should reflect upon and evaluate the impact they have on goal setting interactions. They should endeavor to positively encourage and empower the stroke survivor. They should get to know the person, listening to them and finding out "who they are", in order to develop meaningful goals (together) that are individualized to the stroke survivor (Grade B recommendation[37]).
- Practitioners should recognize that recovery after stroke is ongoing and unpredictable and be aware of the potential importance to stroke survivors of maintaining hope and a sense of forward momentum through the use of person-centered goal setting in stroke rehabilitation (Grade B recommendation).
- Practitioners should use person-centered goal setting processes in stroke rehabilitation that acknowledge and adapt to a stroke survivor's ability and desire to be involved in goal setting (Grade B recommendation).

Recommendations for research *(level 2 heading)*

Further research is required to further develop individualized, person-centered methods of goal setting throughout the stroke rehabilitation pathway, accounting for the individual needs and preferences of the stroke survivor, their stage of recovery and purposes of goal setting within the context of their situation. It has been identified that practitioners have an influential role with respect to empowerment and disempowerment though goal setting interactions. It would be beneficial to explore this further, identifying whether any link exists to practitioner engagement, personality and goal setting style, and what the necessary skills are for successful person-centered goal setting and how these may be taught to practitioners.

There is a gap in the literature related to the experiences of goal setting from the perspective of family members and unpaid carers, and the impact of goal setting on the ability of stroke survivors to self-manage their condition; both warrant further investigation.

Conflict of interest

There is no conflicts of interest in this project.

Acknowledgements *(level **1**eading)*

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Table 1: Initial key words used in search strategy

Stroke (MESH)
Goals (MESH)
Goal Setting ("goal-setting" OR "goal setting" OR "set* goal*" OR "goal plan*" OR "aim*" OR "objective*" OR "target*") ("GAS" OR "goal attainment scal*" OR "COPM" OR "canadian occupational performance measure")
Rehabilitation ("rehabilitation" OR "rehab*" OR "recover*")
Experiences ("experienc*" OR "perception*" OR "opinion*" OR "attitude*")

Table 2: Methodological assessment of included articles

Citation	Question									
	1	**2***	**3***	**4***	**5**	**6***	**7***	**8**	**9**	**10**
Brown et al. (2014) [22]	N	U	Y	Y	Y	N	U	Y	U	Y
Levack et al. (2011) [17]	Y	Y	Y	Y	Y	N	U	Y	U	Y
Martin et al. (2015) [25]	Y	Y	Y	Y	Y	N	U	Y	N/A**	Y
Rosewilliam et al. (2016) [41]	U	Y	U	U	U	U	Y	Y	Y	Y
%	50%	75%	75%	75%	75%	0%	25%	100%	25%	100%

Y=Yes; N=No; U=Unclear; N/A=Not Applicable
*Dependability questions
**N/A rating given as the authors stated in the paper that the study had been deemed by a Regional Ethics Committee as sufficiently low risk as to not require ethics committee review.

Table 3: Synthesised finding 1

Findings (n=16)	Categories (n=3)	Synthesized finding
(4g) Professional-related factors that influenced patient-centredness in goal-setting - Explicit patient-centred behaviours were noticed in empowered professionals. [C] (1r) For those who took part in formal goal setting meetings, the process was viewed as a collaborative effort. [U] (2h) Privileged goals … tended to describe the rehabilitation process rather than drive it. [U] (4h) Patients were unclear about what rehabilitation goals meant or whether they had been involved, as they did not recall being asked for goals. [U]	Person-centred goal setting is possible and "rewarding", but it doesn't always happen.	**Person-centred goal setting is possible but often doesn't occur.** *It is possible for stroke survivors to set person-centred goals with practitioners if both intrinsic and extrinsic affecting factors are aligned positively. However, often this does not occur leading to goals that are not fully person-centred.*
(4b) Limited adoption of patient-centredness in goal-setting local practice - Dysfunctional therapeutic relationship (between patient and professional) either the reason for or effect of non-collaboration in goal-setting. [U] (4c) Patient-related and system-related factors that influenced patient-centredness in goal-setting - patient disempowerment. [U] (4d) Patient-related and system-related factors that influenced patient-centredness in goal-setting - Proactive patient and family facilitated patient specific goals. [U], (4e) Professional-related factors that influenced patient-centredness in goal-setting - work culture within the acute bio-medical model not conducive to patient-centred goal-setting. [U] (1j) Battle versus alliance. [C] (1m) Most participants spoke briefly of the support these people [friends and family] provided, but also sometimes of their role as a source of tension. [C] (1q) The practitioner was seen as the expert and the participant accepted the direction they provided. [U] (1s) Not all participants however felt it important to partake in formal goal setting. [U] (2h) Privileged goals … tended to describe the rehabilitation process rather than drive it. [U]	There is a spectrum of person-centredness, which depends on a variety of factors - intrinsic and extrinsic to the stroke survivor.	
(1e) Participants responded to the uncertainty of stroke by wanting to set extremely ambitious goals that would push them to their highest level of performance. [U]		

(1f) Participants could aim for an ambitious goal, and found motivation from doing so, even when accepting that achievement of that goal was unlikely. [U] (1w) Many participants aimed for ambitious goals - albeit, for some, in secret. [U] (1v) Finding comfort in the ability to imagine achieving seemingly impossible goals ... and gaining motivation and satisfaction from them. [U]	Tension between ambitious and conservative goals, which could lead to goals kept in secret.	

Table 4: Synthesised Finding 2

Findings (n=12)	Categories (n=2)	Synthesized finding
(3l) Staff members were perceived as contributing to, and limiting, pursuit of life goals. [C] (1x) Health professionals could both raise and diminish a patient's sense of hope through their interactions with them. [U] (1o) Positive effects of building alliances with rehabilitation staff members. [U] (1r) For those who took part in formal goal setting meetings, the process was viewed as a collaborative effort. [U]	**Practitioners can either "encourage" people or "deflate" them.**	**Practitioners shape the context of goal setting.** *Practitioners have an influential role in shaping the physical, social, emotional and attitudinal context surrounding rehabilitation goal setting interactions.*
(4c) Patient-related and system-related factors that influenced patient-centredness in goal-setting - patient disempowerment [feeling obligated to participate]. [U] (4e) Professional-related factors that influenced patient-centredness in goal-setting - work culture within the acute bio-medical model not conducive to patient-centred goal-setting. [U] (4g) Professional-related factors that influenced patient-centredness in goal-setting - Explicit patient-centred behaviours were noticed in empowered professionals. [C] (3i) Value placed on life goals (by participants) but reluctance to discuss with staff (fear of burdening or value of goal not being shared). [U] (3k) Risk management systems versus choice and control; participants described a lack of opportunities, or barriers, to enact decisional autonomy. [U] (1p) Where staff did not formally elicit or discuss patient-derived goals, this was never questioned by the participants. [U] (1x) Health professionals could both raise and diminish a patient's sense of hope through their interactions with them. [U] (4i) External factors leading to patient disempowerment: patients perceptions that staff ...appeared relatively busy. [U] (4j) Patients perceived they had no control over gaining information to help make decision. [U]	**Empowered / disempowered** ("…my time here is your time").	

Table 5: Synthesised Finding 3

Findings (n=15)	Categories (n=3)	Synthesized findings
(1a) A day by day momentum. [U] (1c) Small, short-term goals often considered important, rather than goals set too far in the future. [U] (1e) Participants responded to the uncertainty of stroke by wanting to set extremely ambitious goals that would push them to their highest level of performance. [U] (1f) Participants could aim for an ambitious goal, and found motivation from doing so, even when accepting that achievement of that goal was unlikely. [U] (1h) The majority of inpatient goals addressed what participants considered to be survival needs ('common-sense') [for example, independence with toileting]. [C] (1k) Tension also existed when it came to deciding on the number of goals a person should work towards during their rehabilitation. [U] (1l) Progressing forwards seen as vital. [U] (1t) One approach to goal setting was never going to suit all people after stroke. [U] (1y) Symbolic achievements [or 'triumphs', referred to as goals or goal successes, and these boosted confidence, motivation and hope for further recovery.] [U]	Goal setting is not "one-size-fits-all" - different types of goals serve different purposes for different people at different times.	**Practitioners need to listen to the person and know "who they are" – there is a need for an individualised approach to goal setting.** *Stroke survivors expressed a need to be listened to and a perceived need for a more individualised approach to goal setting, reflecting both the needs and preferences of the individual. The goal setting approach should be situated within the context of their connections to other people in their lives and to meaningful participation.*
(1u) What makes me "me" [Goals of special importance]. [U] (1v) Finding comfort in the ability to imagine achieving seemingly impossible goals ... and gaining motivation and satisfaction from them. [U]	What makes me "me" **-** the importance of knowing the individual person in order to set goals of 'special importance'.	

(3a) The importance of being actively integrated, connected and encountering within social relationships was the most important aspect of participant's lives (being "part of things") - family relationships valued especially highly. [U] (3b) Relational connectedness through friendships as an important life goal - involving spontaneity, practical support and a sense of belonging. [C] (3c) Importance of collective connectedness through citizenship, where they could see themselves as contributing to something larger, in contrast to just receiving support. [U] (3j) Opportunities for meaningful occupation and participation were highly valued (by participants), and contributed to the achievement of life goals. [C]	Importance of “being part of things”	

Table 6: Synthesised Finding 4

Findings (n=13)	Categories (n=4)	Synthesized findings
(3d) Being simultaneously unchanged, changed and changing in relation to self-concept and life goals. [U] (3e) Being "unchanged" as a person - personality, strengths, insecurities and skills. [C] (3f) Ability to achieve (...) life goals had altered. [U] (3g) The participants also recognized that, in other ways, they had changed considerably in themselves. [This was often reflected in the sudden change they had experienced in terms of their dependency on others for assistance with daily living]. [C] (3h) The participants talked about being in a state of ongoing progress and recovery. [C]	Being 'simultaneously changed, unchanged and changing'.	**Recovery after stroke is ongoing and unpredictable.** *Stroke survivors perceived recovery after stroke to be a natural, ongoing process that was unpredictable in terms of both rate and extent. Whilst this led to uncertainty and potential difficulty setting goals, the over-riding sense was the importance of maintaining a forward momentum throughout it all.*
(1b) Unpredictability [Rate and extent of recovery is unpredictable, leading to reluctance to commit to goals]. [U] (1c) Small, short-term goals often considered important, rather than goals set too far in the future. [U] (1e) Participants responded to the uncertainty of stroke by wanting to set extremely ambitious goals that would push them to their highest level of performance. [U]	Unpredictability – leads to difficulty setting goals.	
(1a) A day by day momentum. [U] (1i) Progressing forwards seen as vital. [U] (1l) Small, daily goals were viewed as important [when battling with mood]. [U]	Day by day (forward) momentum.	
(1g) Natural progression. [C] (1h) The majority of inpatient goals addressed what participants considered to be survival needs ("common-sense") [for example, independence with toileting]. [C]	Recovery is a natural process.	

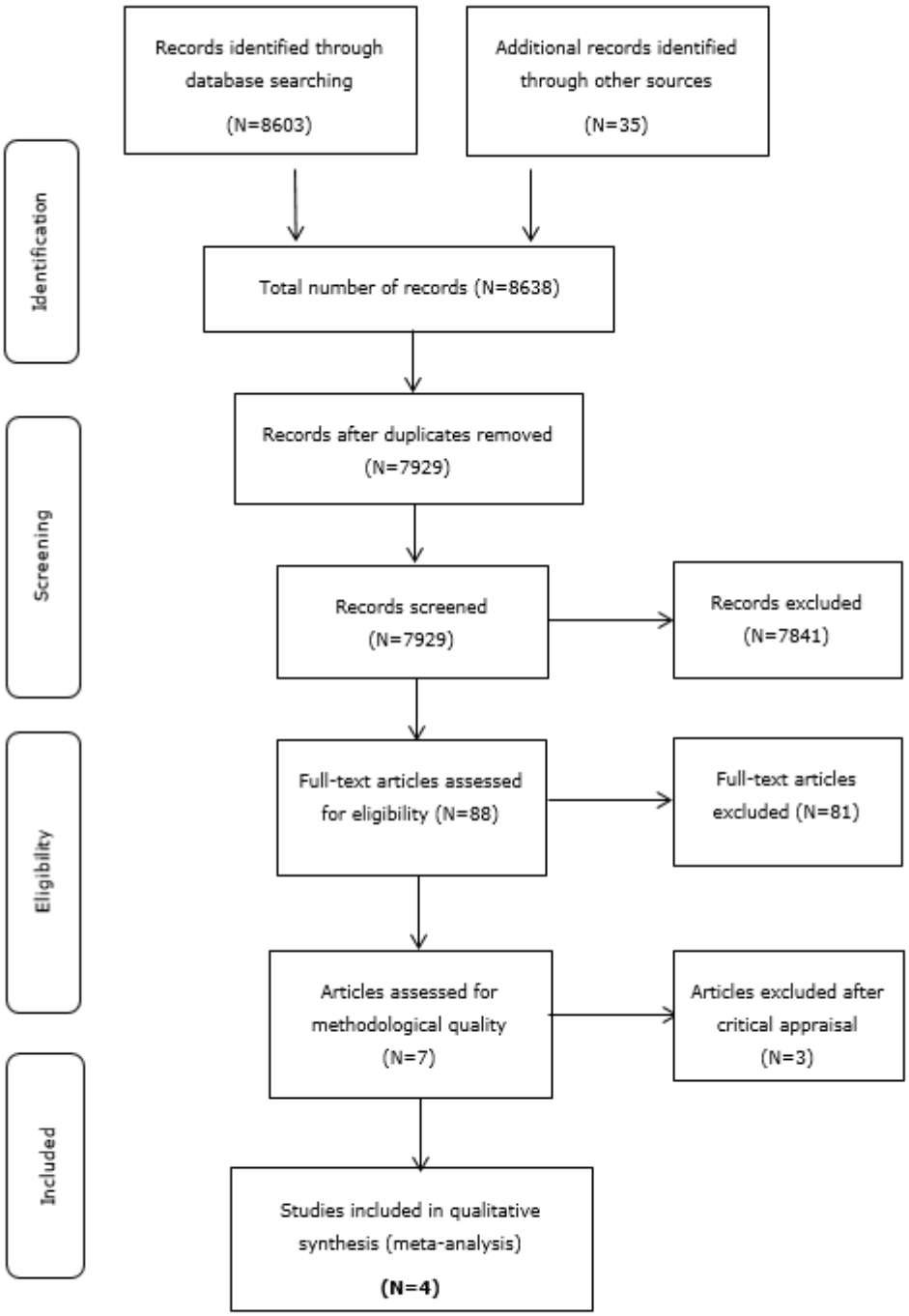

Figure 1: Flow chart of the search and study selection process.[88]

Appendix I: Search strategy

Database searches

Search for published studies: (Start of database until 16th November 2017.)		**Search for unpublished studies:** (Start of database until 16th November 2017.)	
Name	**Hits**	**Name**	**Hits**
MEDLINE	1408	Open Grey	513
Embase	8063	ProQuest Conference Papers and Proceedings	1*
CINAHL	362	Google Scholar	1410 **
AMED	164	Social Care Online (published & unpublished studies)	See earlier
BNI	65	HMIC (published and unpublished studies)	See earlier
Social Care Online (published and unpublished studies)	32	**Author search:** **Databases MEDLINE, CINAHL** (Start of database until 16th November 2017)	
HMIC (published and unpublished studies)	11	Jones, Fiona	113
		Levack, William	58
OT seeker	13	Rosewilliam, Sheeba	9
PEDRO	69	Scobbie, Leslie	19

(Updated searches conducted in November and December 2017)

* The initial search of ProQuest Conference Papers and Proceedings only produced one paper, which was not relevant to this review, and the database was not readily available, so was excluded from the updated search.

** Database excluded after screening 50 pages as no new relevant references were identified.

Example search strategies

Ovid MEDLINE(R)

1 exp Stroke/

2 stroke.ti,ab.

3 exp cerebrovascular disorders/ or brain ischemia/ or exp "intracranial embolism and thrombosis"/ or exp intracranial hemorrhages/

4 Brain Injuries/

5 brain injuries.ti,ab.

6 ((Cerebrovascular or cerebral vascular) and (disease* or disorder* or accident* or trauma*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading

word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]

7 ((Cerebral or cerebellar or brain* or vertebrobasilar) and (infarct* or ischemi* or thrombo* or emboli* or apoplexy)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]

8 ((Cerebral or brain* or subarachnoid) and (haemorrhage or hemorrhage or haematoma or hematoma or bleed*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]

9 (Brain injur* or brain attack or brain damag* or brain-damag*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]

10 (Hemipleg* or hemipare*).ti,ab.

11 (Post stroke or poststroke or post-stroke).ti,ab.

12 Neuro* setting.mp. or neuro* rehabilitation.ti,ab. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]

13 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12

14 exp Goals/

15 goals.ti,ab.

16 (goal-setting or goal setting or set* goal or goal plan* or target*).ti,ab.

17 (Goal* and (set* or plan* or attain* or achiev* or assess* or direct* or orient*)).ti,ab.

18 (GAS or goal attainment scal* or COPM or Canadian occupational performance measure).ti,ab.

19 14 or 15 or 16 or 17 or 18

20 (experience* or perception* or opinion* or attitude* or view*).ti,ab.

21 13 and 19 and 20

22 limit 21 to (english language and humans and "all adult (19 plus years)")

Embase

exp Stroke/

2 stroke.ti,ab.

3 exp cerebrovascular disorders/ or brain ischemia/ or exp "intracranial embolism and thrombosis"/ or exp intracranial hemorrhages/

4 Brain Injuries/

5 brain injuries.ti,ab.

6 ((Cerebrovascular or cerebral vascular) and (disease* or disorder* or accident* or trauma*)).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]

7 ((Cerebral or cerebellar or brain* or vertebrobasilar) and (infarct* or ischemi* or thrombo* or emboli* or apoplexy)).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]

8 ((Cerebral or brain* or subarachnoid) and (haemorrhage or hemorrhage or haematoma or hematoma or bleed*)).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]

9 (Brain injur* or brain attack or brain damag* or brain-damag*).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]

10 (Hemipleg* or hemipare*).ti,ab.

11 (Post stroke or poststroke or post-stroke).ti,ab.

12 Neuro* setting.mp. or neuro* rehabilitation.ti,ab. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]

13 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12

14 exp Goals/

15 goals.ti,ab.

16 (goal-setting or goal setting or set* goal or goal plan* or target*).ti,ab.

17 (Goal* and (set* or plan* or attain* or achiev* or assess* or direct* or orient*)).ti,ab.

18 (GAS or goal attainment scal* or COPM or Canadian occupational performance measure).ti,ab.

19 14 or 15 or 16 or 17 or 18

20 (experience* or perception* or opinion* or attitude* or view*).ti,ab.

21 13 and 19 and 20

22 limit 21 to (english language and humans and "all adult (19 plus years)") [Limit not valid in Embase; records were retained]

CINAHL (Ebsco host)

S33 S18 AND S28 AND S31 Limiters - English Language; Human; Age Groups: All Adult

S32 S18 AND S28 AND S31

S31 S29 OR S30

S30 AB (experience* or perception* or opinion* or attitude* or view*

S29 TI (experience* or perception* or opinion* or attitude* or view*

S28 S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27

S27 AB (GAS or goal attainment scal* or COPM or Canadian occupational performance measure)

S26 TI (GAS or goal attainment scal* or COPM or Canadian occupational performance measure

S25 AB (Goal* and (set* or plan* or attain* or achiev* or assess* or direct* or orient*))

S24 TI (Goal* and (set* or plan* or attain* or achiev* or assess* or direct* or orient*))

S23 AB (goal-setting or goal setting or set* goal or goal plan* or target*)

S22 TI (goal-setting or goal setting or set* goal or goal plan* or target*)

S21 AB goals

S20 TI goals

S19 (MM "Goals and Objectives+")

S18 S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17

S17 AB (Neuro* setting or neuro* rehabilitation)

S16 TI (Neuro* setting or neuro* rehabilitation)

S15 AB (Post stroke or poststroke or post-stroke)

S14 TI (Post stroke or poststroke or post-stroke)

S13 AB (Hemipleg* or hemipare*)

S12 TI (Hemipleg* or hemipare*)

S11 (Brain injur* or brain attack or brain damag* or brain-damag*)

S10 ((Cerebral or brain* or subarachnoid) and (haemorrhage or hemorrhage or haematoma or hematoma or bleed*))

S9 ((Cerebral or cerebellar or brain* or vertebrobasilar) and (infarct* or ischemi* or thrombo* or emboli* or apoplexy))

S8 ((Cerebrovascular or cerebral vascular) and (disease* or disorder* or accident* or trauma*))

S7 AB Brain Injuries

S6 TI Brain Injuries

S5 (MM "Brain Injuries+")

S4 (MM "Cerebrovascular Disorders+")

S3 AB stroke

S2 TI stroke

S1 (MM "Stroke+")

AMED

S33 S18 AND S28 AND S31 Search modes - Boolean/Phrase Interface - EBSCOhost Research Databases

Database - AMED - The Allied and Complementary Medicine Database Edit S33

S32 S18 AND S28 AND S31 Edit S32

S31 S29 OR S30 Edit S31

S30 AB (experience* or perception* or opinion* or attitude* or view* Edit S30

S29 TI (experience* or perception* or opinion* or attitude* or view* Edit S29

S28 S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S2 Edit S28

S27 AB (GAS or goal attainment scal* or COPM or Canadian occupational performance measure) Search modes Edit S27

S26 TI (GAS or goal attainment scal* or COPM or Canadian occupational performance measure) Edit S26

S25 AB (Goal* and (set* or plan* or attain* or achiev* or assess* or direct* or orient*)) Edit S25

S24 TI (Goal* and (set* or plan* or attain* or achiev* or assess* or direct* or orient*)) Edit S24

S23 AB (goal-setting or goal setting or set* goal or goal plan* or target*) Edit S23

S22 TI (goal-setting or goal setting or set* goal or goal plan* or target*) Edit S22

S21 AB goals Edit S21

S20 TI goals Edit S20

S19 (MM "Goals and Objectives+") Edit S19

S18 S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 Edit S18

S17 AB (Neuro* setting or neuro* rehabilitation) Edit S17

S16 TI (Neuro* setting or neuro* rehabilitation) Edit S16

S15 AB (Post stroke or poststroke or post-stroke) Edit S15

S14 TI (Post stroke or poststroke or post-stroke) Edit S14

S13 AB (Hemipleg* or hemipare*) Edit S13

S12 TI (Hemipleg* or hemipare*) Edit S12

S11 (Brain injur* or brain attack or brain damag* or brain-damag*) Edit S11

S10 ((Cerebral or brain* or subarachnoid) and (haemorrhage or hemorrhage or haematoma or hematoma or bleed*)) Edit S10

S9 ((Cerebral or cerebellar or brain* or vertebrobasilar) and (infarct* or ischemi* or thrombo* or emboli* or apoplexy)) Edit S9

S8 ((Cerebrovascular or cerebral vascular) and (disease* or disorder* or accident* or trauma*)) Edit S8

S7 AB Brain Injuries Edit S7

S6 TI Brain Injuries Edit S6

S5 (MM "Brain Injuries+") Edit S5

S4 (MM "Cerebrovascular Disorders+")

Database - AMED - The Allied and Complementary Medicine Database Edit S4

S3 AB stroke Search modes - Boolean/Phrase Interface - EBSCOhost Research Databases

Search Screen - Advanced Search Edit S3

S2 TI stroke Edit S2

S1 (MM "Stroke+")

BNI

1. BNI; exp STROKE/;

2. BNI; stroke.ti,ab;

3. BNI; ((cerebrovascular disorders OR brain ischemia OR "intracranial embolism and thrombosis" OR intracranial haemorrhages)).ti,ab,af;

4. BNI; (brain AND injuries).af;

5. BNI; (brain AND injuries).ti,ab;

6. BNI; (((cerebrovascular OR cerebral vascular) AND (disease* OR disorder* OR accident* OR trauma*))).af;

7. BNI; (((cerebral OR cerebellar OR brain*) AND (infarct* OR ischemi* OR thrombo* OR emboli* OR apoplexy))).af;

8. BNI; (((cerebral OR brain* OR subarachnoid) AND (haemorrhage OR haemorrhage OR haematoma OR hematoma OR bleed*))).af;

9. BNI; ((brain injur* OR brain attack OR brain damag* OR brain-damag*)).af;

10. BNI; ((hemipleg* OR hemipare*)).ti,ab;

11. BNI; ((post stroke OR poststroke OR post-stroke)).ti,ab;

12. BNI; ((neuro* setting) OR (neuro* rehabilitation)).ti,ab;

13. BNI; 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11 OR 12;

14. BNI; goals.af;

15. BNI; goals.ti,ab;

16. BNI; ((goal-setting OR goal setting OR set* goal OR goal plan* OR target*)).ti,ab;

17. BNI; ((goal* AND (set* OR plan* OR attain* OR achiev* OR assess* OR direct* OR orient*))).ti,ab;

18. BNI; ((GAS OR goal attainment scal* OR COPM OR Canadian occupational performance measure)).ti,ab;

19. BNI; 14 OR 15 OR 16 OR 17 OR 18;

20. BNI; ((experience* OR perception* OR opinion* OR attitude* OR view*)).ti,ab;

21. BNI; 13 AND 19 AND 20.

Social Care Online

Keywords: Stroke and Goal

Detailed keywords:

Stroke OR cerebrovascular disorders OR cerebrovascular accident OR brain ischemia OR Brain injury OR brain damage OR Hemiplegia OR hemiplegic OR hemiparesis OR hemiparetic OR Post stroke OR poststroke OR neuro setting OR neuro rehabilitation'

AND

Goal OR goals OR goal setting OR setting goal OR goal planning OR target OR goal achievement OR GAS OR goal attainment scale OR goal attainment scaling OR COPM OR Canadian occupational performance measure'

AND

Experience OR perception OR opinion OR attitude OR view'

NOT

Child or paediatric or pediatric or children or baby'

HMIC

Keywords: Stroke and goal

OT Seeker

'Goal OR goals OR goal setting OR setting goal OR goal planning OR target OR goal achievement OR GAS OR goal attainment scale OR goal attainment scaling OR COPM OR Canadian occupational performance measure' AND [Any Field] like 'Stroke OR cerebrovascular disorders OR cerebrovascular accident OR brain ischemia OR Brain injury OR brain damage OR Hemiplegia OR hemiplegic OR hemiparesis OR hemiparetic OR Post stroke OR poststroke OR neuro setting OR neuro rehabilitation'

PEDro

Stroke AND goal

ProQuest Conference Papers and Proceedings

Stroke AND goal

Open Grey

("stroke" OR "Cerebrovascular Disorders" OR "Brain Injuries" OR "Hemipleg*" OR "hemipare* OR "Neuro* setting" OR "neuro* rehabilitation") AND ("Goals and Objectives" OR "goal-setting" OR "goal setting" OR "set* goal" OR "goal plan*" OR "target*" OR "set*" OR "plan*" OR "attain*" OR "achiev*" OR "assess*" OR "direct*" OR "orient*" OR "GAS" or "goal attainment scal*" OR "COPM" OR "Canadian occupational performance measure" AND ("experience*" OR "perception*" OR "opinion*" OR "attitude*" OR "view*")

Appendix II: Screening and selection tool

STROKE SURVIVOR/FAMILY/CARER EXPERIENCES OF GOAL SETTING: SCREENING AND SELECTION TOOL

Review question: What are the experiences of stroke survivors, and their families and unpaid carers, regarding goal setting within stroke rehabilitation?

Inclusion criteria:

Population = Adult stroke survivors; their family members (who provide direct care and / or live with stroke survivor) and / or unpaid carers (stroke survivors as entire focus of study or extractable sub-section).

Phenomena of interest = Experiences of goal setting within stroke rehabilitation (goal setting as an entire focus or extractable sub-section).

Context = Stroke rehabilitation – acute or community; inpatient or outpatient.

Study design = Any qualitative design (entire focus of study or extractable sub-section).

Reviewer name:	**Date:**

Author:	**Year:**
Title:	
Journal:	

	Include	**Exclude**	**Exclusion code**
Population	Adults stroke survivors Family members Unpaid carers	Adults with other neurological conditions / Paid carers / Professionals / Children	1 (experiences of stroke survivors or their families / unpaid carers not explored) 2 (mixed population study where stroke specific data could not be extracted)
Phenomena of interest	Experiences of goal setting: Entire focus of study / Extractable sub-section	No goal setting/ Goal setting mentioned but not the focus of the study / Refers to goal setting but not experiences of / Not extractable sub-section	3 (no goal setting used / goal setting not the focus / goal setting data could not be extracted)
Context	Stroke rehabilitation: acute / community / inpatient / outpatient	Rehabilitation for reason other than stroke	4 (not stroke rehabilitation, e.g. general neurological rehabilitation where stroke specific data could not be extracted)
Study	Qualitative	No qualitative methodology	5 (not qualitative research or

design	methodology and data: Entire focus of study / Extractable sub-section	or data / Not a research paper / Systematic review of the literature	qualitative data could not be extracted)
Overall decision	**Included**	**Excluded**	**Code:**
Notes:			

Appendix III: Excluded studies and reasons for exclusion

Methodological assessment										
Citation	**Question**									
	1	2*	3*	4*	5	6*	7*	8	9	10
Howe et al (2012)	U	U	U	U	Y	N	Y	U	U	Y
Laver et al (2010)	N	U	U	U	U	N	Y	U	U	Y
Berg et al (2016)	N	U	U	U	U	N	Y	Y	Y	Y
Y=Yes; N=No; U=Unclear; N/A=Not Applicable * Dependability questions										

Howe T, Davidson B, Worrall L, Hersh D, Ferguson A, Sherratt S, et al. 'You needed to rehab …families as well': Family members' own goals for aphasia rehabilitation. Int J Lang Comm Disord 2012;47(5): 511-521.

Reason for exclusion: The method of analysis, i.e. content analysis, is considered to lack congruence with a philosophical perspective that suggests people construct knowledge out of their experience, i.e. learning by doing (constructionism). The essence of the experience (learning) may be lost by a focus on the words at a content analysis level. There was no statement locating the researcher culturally or theoretically and there was no audit trail to support the participant quotes provided. The influence of the researcher on the research was addressed and conclusions based on the data presented. This paper achieved 3/10 'yes' results for the critical appraisal assessment, which was below the cut off set for this review.

Laver K, Rehab MC, Halbert J, Stewart M, Phty M, Crotty M. Patient Readiness and Ability to Set Recovery Goals During the First 6 Months After Stroke. J Allied Health 2010; 39(4): 149-154.

Reason for exclusion: Insufficient detail was provided regarding philosophical perspective, methodology and method of data analysis in order to determine congruence, and participants' voices were not considered to be well represented. The author described collecting quality of life outcome measure data in the methodology, but this data was not clearly reported providing a partial picture of findings. The influence of the researcher on the research was addressed and conclusions based on the data presented. This paper achieved 2/10 'yes' results for the critical appraisal assessment, which was below the cut off set for this review.

Berg K, Askim T, Balandin S, Armstrong E, By Rise M. Experiences of participation in goal setting for people with stroke-induced aphasia in Norway. A qualitative study. Disabil Rehabil 2016; 39(11):1122-1130.

Reason for exclusion: Insufficient detail was provided regarding philosophical perspective and methodology in order to determine congruence. The potential impact of the researcher on the data was addressed but there was no statement locating the researcher theoretically or culturally. Participant's voices were well represented and the conclusions were grounded in the data. This paper achieved 4/10 'yes' results for the critical appraisal assessment, which was below the cut off set for this review.

1 **Appendix IV: Details of included studies**

2

Study	Methodology	Method	Phenomena of interest	Participants	Author's conclusion	Reviewer's comments
Brown et al. (2014)	Qualitative descriptive design.	Qualitative semi-structured interviews – in participants' own homes.	Patient experiences of goal setting.	People recently discharged from inpatient stroke rehabilitation (12 weeks) (n=10). Age range 33-85 years (Mean of 59 years)	Person-centered goal setting is considered an ideal part of modern rehabilitation, but cannot be addressed by one-size-fits-all clinical processes. All participants expressed an overriding desire to maintain a forward momentum towards maximizing recovery and quality of life after stroke.	Research design congruent with results and conclusions. This qualitative study was nested within a pilot clinical trial; four participants were recruited from the intervention group and six from the control group.
Levack et al. (2011)	Constructivist grounded theory.	Multiple data collection methods: Semi-structured interviews; open-recording of clinical sessions and meetings; participant-observation; and review of clinical documentation	The application of goal setting.	Patients undergoing inpatient stroke rehabilitation (n=9), their family members (n=7) and treating clinicians (n=28) (Total n=44). Age range 57 – 92 years.	Certain goals are privileged in inpatient stroke rehabilitation, leading to interactional dilemmas for clinicians. Questions whether 'patient-centered' approach is even possible in this setting.	Congruence throughout study with approach, methods and conclusions. Grades of clinicians were not recorded.
Martin	Interpretative	Qualitative	Life goal	People with severe	There is a need to focus	Good congruence

et al. (2015)	phenomenological analysis.	semi-structured interviews.	planning in rehabilitation.	ABI residing in residential care facility and still involved in active, goal-directed rehabilitation (n=5). Age range 51 – 62 years.	on the social identity and relationships of people with ABI, even severe ABI, and pay greater attention to their changing milieu. Persons with ABI in residential care require increased and more creative support to facilitate life goals attainment.	between approach, data collection, analysis and conclusions. Only data from persons with ABI secondary to stroke extracted (n=3); all similar age range (51-62 years).
Rosewilliam et al. (2016)	Not stated.	Multiple qualitative methods of data collection: Semi-structured interviews; Overt observation of ward rounds and professional meetings; Patient case notes.	The adoption of person-centeredness in goal setting, and factors influencing this.	Adult stroke patients, with no cognitive or communication problems (n=7) and their treating health care professionals (n=7) (physiotherapy, occupational therapy, speech and language therapy, medic, and nurse professionals) (Total n=14). Age range 42 – 84 years.	Limited person-centeredness in goal setting was evident. Recommends professionals need support and training to adopt person-centered principles in goal-setting practice.	Conclusions appear congruent with themes and the data reported. Staff interviewed were all Band 6/7 - specialist / highly specialist roles.

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5 **Appendix V: List of study findings and illustrations**

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Article Reference:	**(1) Brown et al (2014)**
Finding (a)	A day by day momentum [U]
Illustration	"I just took it day by day and I sort of set myself certain things to do… if I felt I got through those fairly good, easily, I just took another step forward sort of style." (Bob) (p1023)
Finding (b)	Unpredictability [Rate and extent of recovery is unpredictable, leading to reluctance to commit to goals.] [U]
Illustration	"Goal setting has always been a bit of a problem I feel, because I don't know what sort of rate, you know, I'm going to be rehabbing at." (Andrew) (p1022)
Finding (c)	Small, short-term goals often considered important, rather than goals set too far in the future. [U]
Illustration	"It just builds your confidence up … definitely, setting smaller goals, and looking at everyday [things] rather than in the future too far ahead." (Fleur) (p1022)
Finding (e)	Participants responded to the uncertainty of stroke by wanting to set extremely ambitious goals that would push them to their highest level of performance [U]
Illustration	"I said to [the physiotherapist] well I want you to set the bar right to the top. Because if I can't get, I said because I may not be able to get there but if you set it at the top I might get it three quarters of the way, or 90%. I said, but if you set 75, I may only get to um 60%." (Andrew) (p1022)
Finding (f)	Participants could aim for an ambitious goal, and found motivation from doing so, even when accepting that achievement of that goal was unlikely [U]
Illustration	"The physio said to me – look, we'll do the best we can but I don't want you to over-expectate (sic) because if you don't do it, I don't want you to come crashing down, you've got to realize that you might plateau off. So at the back of my mind I always thought yep I can see that, but I'm going to bloody well walk before Christmas. I just didn't share it with anyone. I just told myself." (Janet) (p1022)
Finding (g)	Natural progression [Recovery after stroke as a natural process] [C]
Illustration	'Central to all participants views was the notion that recovery after stroke was a natural process.' (p1022)
Finding (h)	The majority of inpatient goals addressed what participants considered to be survival needs ('common-sense) [for example, independence with toileting] [C]
Illustration	'These goals were frequently described as being common-sense, and that "it was kind of apparent what needed to be worked on."' (Ian)(p1022-3)
Finding (i)	Progressing forwards seen as vital [U]
Illustration	"Having something to aim for is important, otherwise you stagnate." (Colin)(p1023)
Finding (j)	Battle versus alliance [C]

Illustration	'Some factors, such as the encouragement of others, assisted participants to maintain their determination, and their sense of momentum in recovery. Other factors, however, curbed their determination, creating a sense of having to do 'battle' in their recovery – battling against the condition, but also in some instances against other people and the health system.'(p1023)
Finding (k)	Tension also existed when it came to deciding on the number of goals a person should work towards during their rehabilitation [U]
Illustration	"If you place too many goals on yourself I think you can stress yourself out in the process." (Janet) (p1023)
Finding (l)	Small, daily goals were viewed as important [when battling with mood.] [U]
Illustration	"… if you set goals you could achieve everyday, I think it would keep lifting you." (Fleur) (p1023)
Finding (m)	Most participants spoke briefly of the support these people [friends and family] provided, but also sometimes of their role as a source of tension. [C]
Illustration	'Ian noted "you're constantly battling people's perceptions of what you're capable of and what you should be doing."' (p1023)
Finding (o)	Positive effects of building alliances with rehabilitation staff members. [U]
Illustration	"… they could see that I was trying [so] they helped me more and more." (Bob) (p1023)
Finding (p)	Where staff did not formally elicit or discuss patient-derived goals … this was never questioned by the participants. [U]
Illustration	'Some participants perceived there was already "a set plan … they had a plan to work to and we just plodded our way through it."' (Gary) (p1023)
Finding (q)	The practitioner was seen as the expert and the participant accepted the direction they provided. [U]
Illustration	' "I was the novice", commented Ian, "and they were the professionals."'(p1023)
Finding (r)	For those who took part in formal goal setting meetings, the process was viewed as a collaborative effort. [U]
Illustration	"Stroke recovery is to a certain extent unpredictable and that's why [health professionals] are learning as they go … and they're learning from people like me … I found that rewarding, that it was an equal interaction if you like, not a, well the old-fashioned patient-nurse situation." (Colin) (p1023)
Finding (s)	Not all participants however felt it important to partake in formal goal setting. [U]
Illustration	"...well because my goals were my goals…the less I talked in hospital the better I was, really. I don't want to keep going over and over and over. Within myself I have worked out a wee sort of plan which may or may not work and I don't want to be continually patted on the back or commiserated with – I just want to be able to set it in motion." (Janet) (p1023)
Finding (t)	One approach to goal setting was never going to suit all people after stroke. [U]

Illustration	"Work back from personality, if you like, to the goals … you know, listening to the words, listening to the patient, um knowing who they are is important … you'd feel involvement rather than um, how can I put it, [that goal setting was] a bureaucratic exercise." (Colin)(p1024)
Finding (u)	What makes me “me” [Goals of special importance]. [U]
Illustration	"… I’m not fighting for my life, but I’m just fighting for my lifestyle, in other words what makes me “me.” “ (Colin) (p1024)
Finding (v)	Finding comfort in the ability to imagine achieving seemingly impossible goals ... and gaining motivation and satisfaction from them. [U]
Illustration	"I think as normally as possible and then I’ll go to bed at night and think oh well I won’t be doing that really. But that’s okay because at sometime I will. And if I don’t do them, I can dream about them … I can lie in bed and dream about climbing a mountain, cos I just adore mountains …" (Janet) (p1024)
Finding (w)	Many participants aimed for ambitious goals- albeit, for some, in secret. [U]
Illustration	"The physio said to me-look, we’ll do the best we can but I don’t want you to over-expactate (sic) because if you don’t do it, I don’t want you to come crashing down, you’ve to to realise that you might plateau off. So at the back of my mind I always thought yep I can see that, but I’m going to bloody well walk before Christmas. I just didn’t share it with anyone. I just told myself." (Janet) (p1022)
Finding (x)	Health professionals could both raise and diminish a patient’s sense of hope through their interactions with them. [U]
Illustration	"I heard the words and they had some impact, but there was still an underlying spirit, if you like, thinking well let’s see what we can do. Not let’s – let’s not say what we can’t do … it is not wise to set negative goals, or set limitations when you know [stroke recovery] is unpredictable … learn how to encourage people and not deflate them." (Colin) (p1024)
Finding (y)	Symbolic achievements [or ‘triumphs’, referred to as goals or goal successes, and these boosted confidence, motivation and hope for further recovery.] [U]
Illustration	"It’s usually a revelation if you like, it’ll be a minor one like um, oh I can open the door easier … A little triumph I had yesterday, um I cut my fingernails twice with this hand. That’s the way of gauging progress you know, in something like that … I can say oh in those two weeks that has significantly changed. So that’s you know, a boost." (Colin) (p1024)
Article Reference:	**(2) Levack et al (2011)**
Finding (h)	Privileged goals … tended to describe the rehabilitation process rather than drive it. [U]
Illustration	"They [the physiotherapists] certainly had an interest in the game of bowls and the fact that I was you know a bowler and had bowling as a hobby … but they didn’t set any special plan I don’t feel, to suit a bowling action … they studied me – they made me bring my bowls to the hospital … But the exercises I was performing didn’t change, they were the same exercises priori to seeing me bowl and they kept up the same exercises after. They didn’t change them at all." (Interview with P3, three months after discharge) (p211)

Article Reference:	**(3) Martin et al (2015)**
Finding (a)	The importance of being actively integrated, connected and encountering within social relationships was the most important aspect of participant's lives (being "part of things") - family relationships valued especially highly [U]
Illustration	"In here I want to rehabilitate myself to the extent I can go home, and be in a home by myself, and have my son ... and do the right thing by my boy." (Sarah) (p1236)
Finding (b)	Relational connectedness through friendships as an important life goal - involving spontaneity, practical support and a sense of belonging. [C]
Illustration	"Just ringing them in the odd day, and [my friend] comes in quite a bit and sees us." (Bridget) (p1237)
Finding (c)	Importance of collective connectedness through citizenship, where they could see themselves as contributing to something larger, in contrast to just receiving support. [U]
Illustration	"It's very important for me to be able to help people ... it's obviously good for them that I'm helping them, but maybe this is selfish, it's very, very important for me that I'm helping them." (Megan) (p1237)
Finding (d)	Being simultaneously unchanged, changed and changing in relation to self-concept and life goals. [U]
Illustration	"No, I'd say the [things that are important to me] are pretty much the same, but it's my ability to be able to achieve them which has changed." (Megan) (p1237)
Finding (e)	Being "unchanged" as a person - personality, strengths, insecurities and skills. [C]
Illustration	'Bridget described herself as previously being an "outgoing" and "loud" person who "just wanted to get up and do things, get things done". When asked how she would describe herself now, she responded: "I'm probably still a bit loud. I like going to see friends that sort of thing. And going out."' [Bridget] (p1237)
Finding (f)	Ability to achieve (...) life goals had altered [U]
Illustration	"No, I'd say the [things that are important to me] are pretty much the same, but it's my ability to be able to achieve them which has changed." (Megan) (p1237)
Finding (g)	The participants also recognized that, in other ways, they had changed considerably in themselves. [This was often reflected in the sudden change they had experienced in terms of their dependency on others for assistance with daily living. [C]
Illustration	'Megan described herself as being "terribly different" as a person, particularly in regard to not being able to use the left side of her body and the impact that this had on her independence with physical tasks.' (p1237)
Finding (h)	The participants talked about being in a state of ongoing progress and recovery. [C]
Illustration	'For example, Bridget referred to her past inability to "walk, talk, or do anything" and contrasted this with the statement: "now I'm working for them."' (p1237)
Finding (i)	Value placed on life goals (by participants) but reluctance to discuss with staff (fear of burdening or value of goal not being shared). [U]

Illustration	“I don't like to prattle on, you know. People are helping me on my day-to-day necessities, and I don't therefore want to burden them with 'oh, I really want to be doing this.' ... I should be grateful for, and encourage the help in the ways that I do get it, because of course it is invaluable to me to get that help. And I don't want to diminish that in any way.” (Megan) (p1238)
Finding (j)	Opportunities for meaningful occupation and participation were highly valued (by participants), and contributed to the achievement of life goals. [C]
Illustration	‘For Bridget, the value of occupation was most clearly viewed through the lens of her vocational role. Her part-time employment allowed her to experience "the independence of working" and facilitated her connections with people. "The people I work for ... and the customers ... I can chat away. Yeah, no, it's good. Really good ... Being friendly. That sort of thing."' [Bridget] (p1238]
Finding (k)	Risk management systems versus choice and control; participants described a lack of opportunities, or barriers, to enact decisional autonomy. [U]
Illustration	"Well I think to be able to make independent choices about how I want to spend my day, for instance, and where I want to go, and to be able to just do it, without having to beg and plead." (Megan) (p1238)
Finding (l)	Staff members were perceived as contributing to, and limiting, pursuit of life goals. [C]
Illustration	‘The participants described the importance of external validation from staff, including the need for recognition of mastery over small goals when describing their successes. The support and encouragement for small gains communicated faith in them as a whole person. They talked about the need to share ideas with staff, and the importance of telling staff their goals.' (p1239)
Article Reference:	**(4) Rosewilliam et al (2016)**
Finding (b)	Limited adoption of patient-centeredness in goal-setting local practice - Dysfunctional therapeutic relationship (between patient and professional) either the reason for or effect of non-collaboration in goal-setting [U]
Illustration	‘Field notes about the MDT meeting observed for patient 6: Nurse reported 'he (patient 6) attempted to throw the jug at her the other day. He is not totally aware of his issues'. In his interview on questioning about getting involved with goal-setting Patient 6 said, "If you (staff) won't come and talk to me as a patient what can I do? ...I don't want to be a pain in the neck..."' (p513)
Finding (c)	Patient-related and system-related factors that influenced patient-centeredness in goal-setting - patient disempowerment [feeling obligated to participate] [U]
Illustration	"You see my time here is your time. I have to abide by your rules. When I am out of here I abide by my rules..." (Patient 2)(p513)
Finding (d)	Patient-related and system-related factors that influenced patient-centeredness in goal-setting - Proactive patient and family facilitated patient specific goals. [U]
Illustration	"It's definitely up to the individual how fast they recover. How far they go ... I think if you want to make it better you can improve the situation by having a regime and a goal I want to get there..." (Patient 2)(p514)

Finding (e)	Professional-related factors that influenced patient-centeredness in goal-setting - work culture within the acute bio-medical model not conducive to patient-centred goal-setting [U]
Illustration	"I think their goals are to get you off. I don't think the hospital has got enough (staff). After me there's another queue coming in ..." (Patient 2) (p515)
Finding (g)	Professional-related factors that influenced patient centeredness in goal-setting -Explicit patient-centred behaviors were noticed in empowered professionals [C]
Illustration	'For patient 1 the doctor conveyed hope as he discussed recovery prospects, an aspect that other professionals do not want to discuss due to the unpredictable nature of stroke recovery.' (p516)
Finding (h)	Patients were unclear about what rehabilitation goals meant or whether they had been involved as they did not recall being asked for goals. [U]
Illustration	"What kind of goals? I am not that young you know" … no one's asked me. Apart from you … if I leave here I have to go and sort out myself, my way" (Patient 3)(p514)
Finding (i)	External factors leading to patient disempowerment: patients perceptions that staff ...appeared relatively busy. [U]
Illustration	"Don't get the stress of the staff here because they haven't got the time they don't want to get involved. They've to make beds, give drugs, give injections, they haven't got the time for this..." Patient 2 (p514)
Finding (j)	Patients perceived they had no control over gaining information to help make decision. [U]
Illustration	"…because you are in your bed all you do is function, your eating… and wait for the doctors to come around … you don't know when .. You will forget the question by the time they come…" Patient 1 (p514)

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